



Stillbirth Happens – let's talk

E03: Asking questions, finding answers

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ERIN: Hello, and thank you for joining us on Stillbirth Happens - let's talk. It's a new podcast brought to you by the Hummingbird Project and BC Women's Hospital. I'm Erin.

JAIME: And I'm Jaime. If you've been listening to our previous episodes, you'll know that we're both moms who have given birth to stillborn babies.

We became friends and have been working together since 2013, helping to bring stillbirth out of the shadows.

ERIN: We don't know the details of your story. You may be a bereaved parent, a family member, or a clinician. We do know, if you're listening to this podcast, it's because stillbirth has touched your life in some way.

JAIME: Stillbirth is a profound experience. If it happens to you, you just have so many questions. It's so important to be able to ask about what *you* need to know and to articulate the kind of help *you* need from the people around you, speaking up, finding community and being heard. That's what this episode is all about.

ERIN: So welcome. We want you to know this is a safe space to grieve. And hopefully find company through listening to other stillbirth stories that help you as you go forward on your journey.

JAIME: I think it's worth giving a brief definition here. In Canada, stillbirth is defined broadly as the death of a baby after 20 weeks gestation or greater than or equal to 500 grams that occurs before they are born. The definition of stillbirth in Canada includes ending a pregnancy at or after 20 weeks gestation when a baby is diagnosed with a life-limiting medical condition prior to birth. This is commonly known as termination for medical reasons, or T.F.M.R.

Stillbirth, including termination for medical reasons, and the questions that surround it, can give rise to powerful emotions. Today we hear the story of a bereaved parent who struggled making the decision to terminate after learning her baby's diagnosis. She will share the many questions she had and what helped her most during and after the experience.

ERIN: We'll also hear from a caregiver, an OB/GYN, who works with bereaved families and who has experienced a stillbirth herself, about how she navigates the tough questions that parents have around stillbirth.

Courtney is many things, but mom is a role she is most proud of. Courtney is mother to three boys: Luca, who was stillborn at 23 weeks and three days, her living son Bodhi, who is seven months old, and her stepson Kai, who is seven years old.

JAIME: At their routine 21-week ultrasound Courtney and her husband Jasyn learned Luca had serious and life altering medical abnormalities that threatened his ability to thrive in life. As they navigated two hospitals, one local and the other, a four hour drive away. Courtney and Jasyn were faced with making a difficult decision. Courtney, thank you so much for being with us today.

COURTNEY: Hi ladies, thanks for having me.

ERIN: Courtney, will you share Lucas's birth story with Jaime and I?

COURTNEY: Yeah, my husband and I, we were so blessed with, um, a pregnancy after trying for a year and a half. He was shift work, so it was very tricky to actually get a pregnancy in there, and when it happened, we were over the moon.

I went into my 21 week ultrasound with my, uh, stepson. We were so excited and we're sitting in the ultrasound and I could just tell something was off. She wasn't congratulating my son. She wasn't interacting with us. And what I then found out two days later is that my little boy had severe abnormalities. Our son was diagnosed with spina bifida myelomeningocele.

So there's three degrees of spina bifida, and then is there the most challenging one, and that actually caused a cascade of other effects on, um, our son. In turn, he had Chiari II malformation and from there severe hydrocephalus on the brain. So obviously grave diagnosis that was pretty hard to take.

But yeah, from there we, as a family, really spend some time together and make some decisions and that's kind of where it all began.

JAIME: Courtney, thank you for sharing. I have two sons that were both stillborn and they were stillborn three years apart. And with my first son, James, we too walked a a path of difficult diagnosis from about 18 weeks. We share some similarities in that respect.

COURTNEY: Wow. I, I see it's the club you never wanna be a part of, but once you're in it, you meet some spectacular people and you could have some pretty amazing connections through all the pain.

JAIME: Absolutely. Courtney, if you think back to when you first learned of Lucas' diagnosis, what questions ran through your head?

COURTNEY: Oh, I think the biggest one was like, how sure are you, come on, really?

I think there was: can we follow through with this? What are our options? How serious is this? What kind of life would a child with this diagnosis potentially have? And as a family, what can we handle? It was hard. It was very hard and there was a lot of talk with family members. There was a lot of honest, honest talk with individuals; they could just share their own path and what it might look like for us. And it was just difficult, all of it really.

[music interlude]

JAIME: You and your husband were faced with having to make what must have felt like an impossible decision. Did you feel you had sufficient information to make the decision that was right for you, Luca, and your family?

COURTNEY: I thought at the time I got I had all the information I needed. I felt very confident in my decision. Obviously devastated, but confident that we were making the right decision for not only our

son Luca, but for our family. And I thought, that the medical staff provided us concrete information. But if I reflect now with the knowledge I have now, I don't necessarily believe that anymore.

JAIME: Mm-hmm.

COURTNEY: I, I wish I would've pushed to see the neurologist. I wish I would've pushed to maybe find a family that actually chose differently and what was their life like, what did it look like? And even exploring the option of the fetal surgery. There's just so many different things that... it felt like I had to make a decision so quickly, and yeah, I think I, I likely wouldn't have changed my choice, but I think I would've had less questions now.

JAIME: I think back to that time and, and I, I remember a five-week period where we were faced with many appointments and had many questions ourselves, and, even though I was being provided with so much information, it just felt so surreal. I, I can't describe it any other way. Prior to us making our decision, James passed away and so he died in utero and then was stillborn. But, I remember those appointments vividly and hours, days spent at the hospital in, in seeing different professionals throughout the day. So yeah, it's bringing me back, uh, some memories here.

COURTNEY: Yeah, I bet.

JAIME: Reflecting on that time, do you feel there are resources or supports that could help others as they navigate such a situation?

COURTNEY: I definitely do. First of all, I wish I understood the acronym T.F.M.R. - termination for medical reasons. So if you put that hashtag in Instagram or if you Google it, you're gonna find so much more. 'Cuz I remember trying to prepare. I was, it was the first time I was going to give birth. And yet I was provided information from the fetal medical team that, oh, it will just be like period cramps, and it was not like period cramps. It is a, well, you are giving birth, it is a smaller size child obviously, but you are being induced and you're contracting and you're, I had an epidural. And you go through all of it in a, not the exact same way, but, it is still giving birth.

Significant things your body's going through. And that right there is still your birth story. You still have control over some parts of it. So what comforts you? What's important? Do you want scent in the room? Who do you want in the room? Do you want it to be dim lights and very private? Like, mine took a long time, it was three days that it actually took me to deliver my son. Some people it's hours, but you still have control.

JAIME: For sure, and I, I share that as well. I asked all of those same questions I think that you did. What is it gonna be like? With my daughter, she was my first, and I had a c-section with her. But with James, I delivered him. So it was my first experience with delivering vaginally and absolutely it was full on labour and birth, and it wasn't just cramps.

So, yeah, that message for sure it is your birth story and how we want to deliver needs to be part of that.

COURTNEY: Definitely. I found too is I went from having this safe kind of haven of my midwife and then she's like, I have to give up care. You're being transferred now. So I then lost that security and I even remember trying to find a bereavement doula just to make it as comfortable and supported as we could, so...and I was very lucky, my husband was, was awesome. And, yeah.

[music interlude]

JAIME: So what about in the weeks and months after you gave birth? Were you able to get answers to some of your questions then?

COURTNEY: So for those that don't know, spina bifida is a neural tube defect, and that's why we take folic acid when pregnant is to hopefully lessen the likelihoods. And I was that 20%, that was the unlucky one that it still happened.

So for us, we had concerns about obviously subsequent pregnancies, but the questions didn't come up 'til later, could I have had palliative care for my son? And it's interesting that I was talked out of talking to a neurologist and I was given comments like, "well, we wouldn't wanna get your hopes up."

ERIN: I think what so many people try to do is they try to protect us because we're hurting and it's sad news, and everybody wants to intervene and make everything happy and put a spin on it.

When in reality we don't need protecting, we just need support. We need to be heard, and it is so sad that instead of supporting you, in answering your questions that you were already talked out of it, or "you don't need that". It's just, that's where so much of your power as a mom is gone, taken away from you, right? You were just simply asking questions that other people are uncomfortable with, but you're still a mum regardless.

COURTNEY: No, Erin, I definitely found that. I found everybody was so sad. And like, you get put in the sad room, everybody like has a, a grim face on and is like, would you like a tissue? And I just turned into survival and I kind of switched off a lot of that emotion. I was like, I'm here for the facts, give me the details, I'm collecting data, and I'm making the best decision, so I'm sorry, but I don't actually want your sadness because I'm collecting facts, so...

ERIN: right.

JAIME: Yes.

ERIN: Or you get the people with those poor you eyes and I'm thinking, don't poor me, there's nothing poor me. But it's like they see you in this one light where it's all doom and gloom and they wanna make it sunshine and rainbows, but it's actually like, no, this is just life and we are dealing, we are here. We are showing up.

COURTNEY: I think it, what you reminded me, Erin actually was, so I really wanted to own my story. My husband and I, we both wanted to own it. We understood this stigma associated with termination for medical reasons, and we also found out that the majority of people hide it because they're scared or they feel shame or embarrassment, or they're just so devastated, and my husband and I were like, we need to be vocal about this. We need to step out of our being uncomfortable and just show up for people that are too scared to, and show them that it's it's okay. And that maybe if one person reaches out to us because we owned our story and we were able to help them, that's all that mattered.

So we actually took it into our hands and wrote a big, big email and we sent it out to everyone and it was just like, this is the facts, this is the story, and this is our beautiful journey. We still found beauty and such a tragedy of losing our son. We were like, we're owning this. We're not leaving it any room for anybody else to run with our story.

JAIME: and that's so important.

ERIN: So, from there, Courtney, what resources did you find most helpful after you gave birth?

COURTNEY: There is a organization called Mamas for Mamas, and they were a huge help. They offer free counseling and when I spoke to them initially, they were like, "do you need, do you need a nutritionist? Do you need, what can we do for you? Do you need any partum care?" They were just so incredibly open and welcoming, and I did take them up on counseling, so that was a huge help.

There was the community of T.F.M.R. Mamas, so if you, again, on Instagram, there's quite a few. Emma Bell is a huge leader and she's started support groups and there's just, there's so much more out there than I would've ever thought.

JAIME: Can I circle back to your email that you said that your husband and you sent out, and what kind of response did you get from your loved ones or from the group that you sent it out to?

COURTNEY: Ooo, I think it was surprising actually, 'cuz we sent it out like my husband sent it to colleagues. We had to explain how this, this, um, pregnancy was just gone suddenly and we received responses that were just the most compassionate, vulnerable and connecting from people we would've never imagined. People I didn't think I had much of a connection with but through that email it's changed.

And we had people that would respond and say, "I don't, I can't..." sorry, uh, would say, "I don't even have words to respond to what a beautiful email you sent", and... but then there was also people that were silent and you remembered the people that were silent.

JAIME: Courtney, we'd love for you to share with us what is it that you are really thankful for, for the time that you were able to spend with Luca?

COURTNEY: What ended up being the most important thing is a beautiful friend recommended that I pick out a special blanket to bring and wrap my baby in. And so I picked out a blanket and I wrapped my, my sweet Luca in the blanket. And then when I left, I cut it in half and I wrapped my baby up with the half of it. And then I, and then I took that other half home with me.

I also had two different little hats for him, so I took the hat that had been on his head and I replaced it, and then so I took one home with me. And those two pieces ended up being instrumental in my healing and grieving because of the scent. I, I didn't even think about it at the time, but to be able to come back to that smell of my baby was so important and comforting. And it was really, really special. And when I was having really hard times, I could go back to that.

And they talk about scent a lot when you're delivering a live baby and how important that is for bonding. And there is no talk about it in the bereavement process. And I think there needs to be more of it. And that would be my biggest recommendation and is, um, if you're comfortable, bring a blanket and then take some home with you so you do have something that was physically on your baby.

JAIME: I had a blanket actually for each of my boys. One friend had made one when James was stillborn, and then a different friend knit me one for, for Zach, and I struggled leaving the hospital, taking the blankets with me because I wanted them to be with the boys.

But at the hospital they had actually given us a blanket as well. And so I left the blanket with them that they were wrapped in at the hospital and I actually, I brought home the blankets that my friends had made for me because my boys were wrapped in them.

And so, I I know in the early days and the early years, I used to have them with me all the time, the blankets, I still have them in a very special place, and when I need to, I, I bring those out. So I, I absolutely love the idea of bringing the blanket and cutting it and so both you and Luca have a piece of that. That, that's lovely, thank you for sharing that.

COURTNEY: I love that you did that. Jaime, did you, do you remember smelling it like...?

JAIME: Yes! Those are probably some of the most important mementos I have of the boys was knowing that I held them in their blankets and they were, yeah, a huge part of my healing process as well.

ERIN: I did not do the blanket thing. I wish I would've known this story, but I did swap hats and I put Ryann's hat in a Ziploc bag. So, every year on her birthday I would smell it. So yeah, having something that your baby touched is, as you said, needed for the grief journey. Thank you so much for sharing, Courtney.

[music interlude]

JAIME: As Courtney has been saying, there are so many little things that people can do along the way to help grieving parents. From answering their medical questions, to just showing up. Caregivers at the hospital are on the front lines when it comes to supporting families around stillbirth. And as we've heard on this podcast, experiences at the hospital can vary widely.

To find out more about how caregivers can best support grieving parents, we've reached out to one very special OB/GYN, who understands stillbirth personally. Take a listen.

MEGAN O'NEILL: My name is Dr. Megan O'Neill. I'm an obstetrician gynecologist. I practice a wide range of maternity care, including general gynecology, but I have a very special interest in pregnancy after loss and pregnancy after complicated or traumatic pregnancies. Ever since my son, George, was stillborn at 33 weeks, I find my personal experience impacts my clinical practice immensely. I think one of the parts of my journey that helps the most is my understanding of how traumatic it is to lose a child, the associated guilt that comes with this, the trauma, the anger, and then, you know, hopefully one day, a bit of healing that comes with a process of grieving and working through the loss of your child.

I think back to what helped me through it: I was in residency at my training during this time, and even though I had a lot of knowledge of the process of delivery after stillbirths and reasonings behind it, I still had unanswered questions and still had needed people in my corner and my clinicians to kind of help me through this.

I think one of the biggest things I try to incorporate with supporting families who are bereaved or have lost a child, is just not being uncomfortable with grief and child loss. I think as a clinician or a medical professional, we get asked questions from bereaved parents that are often very challenging to answer – “why did my baby die?” You know, “was there a reason for this?” “Could this have been prevented?” Questions such as these.

I think a lot of us know inside of medicine as well as the parents that are going through this that much of the time, we don't have a specific reason why their baby died. And I think that is often a challenging thing to communicate to patients and also for patients to hear.

There's so much emotion involved in these questions and I think it's just important to let those emotions be, let those families have them, validate those feelings. It's okay to be angry. When colleagues or other clinicians ask me about advice regarding how to support these families or how to deal with those challenging questions from bereaved parents. I often explain that it's less about the medicine and much more about the approach and the support that you can offer them.

I think it's so important to recognize the possibility of maternal guilt and really emphasizing, often to the mother specifically, that it's nothing they did and not their fault.

Words can be so impactful, both in a positive, and, also unfortunately, a negative way. These patients will likely hold on to those positive interactions and words of support that they get given. But I think equally so, hurtful comments or questions can be really difficult to hear and then also continually processed during your journey.

For instance, if a family is considering another pregnancy, or even shortly after their stillbirth, I think many people in society view having another baby after child loss or stillbirth, healing, which you know, for a lot of people there is an element of healing, but also they're not replacing that child. So questions such as, "Are you gonna try again?" are probably less helpful than say questions such as if or when they decide to grow their family or add a sibling to the child they lost. Just recognizing that that child was born and is part of their family.

Just like any parent, they often wanna share the story of their child, their birth, their celebrations, their journey, and I often find, you know, such a healing part of their journey is, uh, sharing their story. So as a clinician, learning how to integrate that into the conversations with bereaved parents and dealing with those challenging questions can sometimes be healing and supportive. In an environment where you may not have all the medical answers or solutions to questions that these patients have.

[music interlude]

ERIN: So back to you, Courtney. Now that some time has passed, are there still certain questions that you're holding onto or wondering about?

COURTNEY: I think as, as a mom, you wonder the 'what ifs?', you know? You think about what life would be like. And of course, I, I now have a, a beautiful baby boy because I did get pregnant quite quick after, and I wouldn't have him if I had Luca, so that duality it, that's, that's pretty hard on the heart.

ERIN: I gave birth to my youngest, Quinn, 13 months after Ryann died. So we got pregnant within five months of her death. So, the emotional impact of feeling like I didn't even fully grieve Ryann before I got pregnant again. It's, so tough.

But one of the things that definitely helped me was my nurse telling me at the hospital about how whatever you choose to decide now, when I was in there with Ryann, when you have to make all those quick decisions like you had to make, to be gentle with myself later on. Because for right now, I'm making that choice based off of the information I have now, and later on when I find out more, I'll probably change my decision, but she was like, please don't beat yourself up because you're making the choices you're making based on the information you have. So, that helped me provide grace. For myself, anyway.

COURTNEY: Yeah, I was pregnant two months after and it was a surprise, a very lovely surprise, but still two months after I'm, the grieving, I probably skipped a lot of it, and I'm still going through it slowly, but I like that we have to give ourselves grace.

JAIME: Absolutely.

ERIN: So Luca was stillborn in 2021. In the past two years, what have you learned about T.F.M.R. specifically and the best way people can get their questions answered?

COURTNEY: To reach out to other moms and try to form a community, try to become a part of a community. There's so many options and so many people that have gone through it, and termination for medical reasons is so broad. There's so many different diagnosis and avenues that I think there is

a community for everyone. Definitely, and you need to find your people because they're the ones that understand, they've walked the path.

And unfortunately, I don't know with grieving in general, if people haven't lost someone, they just don't get it the same. And I found that some friendships have ended, just naturally, but people didn't understand. And the grief process in general, it's a wave. It can be a tsunami, it can be so many things.

ERIN: Hmm, exactly. There's people who say, some things that you can never forgive...

COURTNEY: Yeah.

ERIN: Or never forget.

COURTNEY: People are so uncomfortable with grief, so a lot of people say nothing, and that was one part about sending our email to everybody is that we don't want you to pretend this didn't happen. Our son died. He was a part of us. I'm I'm a mom now. If you don't acknowledge him, you're not acknowledging a part of our family and, and a significant part of our lives. And it's incredibly important for us to talk about it, and I want you to ask me about him. And I wanna talk about my baby boy and I, there's, there's still beauty in it. Uh, we still created something so special and had time with him and...

ERIN: He's, he's family.

JAIME: He's family. And for me, my boys gave me so much and I learned so much about myself and yeah, they're a part of who we are and they will never be forgotten.

Before we say goodbye, Courtney, I know that you've been doing work to raise awareness about stillbirth. What does that kind of awareness raising work mean to you personally?

COURTNEY: Reducing the stigma. My main goal is I'm gonna talk and I'm going to be open and vulnerable and be willing to cry with whoever wants to cry with me, because it happens and it happens so much more than I'd like to imagine. And unfortunately, so many people go through it in silence, and that breaks my heart, and so many people go through it without the support that I had and I couldn't imagine. Well, especially going through it maybe in a, a community that doesn't have the, the education and training, we were so blessed to be experiencing something so tragic in an environment that is so supportive.

And there's a community out there, and I want everybody to know that if you're going through it, you're not alone. And you, you might be surprised that somebody in your close circle has gone through it and label it a miscarriage or that is, yeah, suffering in silence. And I just, I don't want that.

JAIME: I'm so with you on that, Courtney. And again, uh, this is why we do what we do and why we're sharing and why we're talking today, so that we are hoping to, to help break that stigma, to talk about it and to make sure that others know we are out there, there are people that can connect with each other.

ERIN: Courtney, thank you so much for taking the time to share with us today. Your story will help other families who are navigating stillbirth.

JAIME: Yes, thank you, Courtney. It's, uh, been really great meeting you and, and talking with you today.

COURTNEY: Well, thanks Erin and Jaime. It's a hard road and it's a devastating road, so you don't have to go at it alone.

JAIME: Great advice.

And thank you so much for joining us to listen to Courtney and Megan. Please join us whenever you can and share this podcast with anyone who needs it. Take good care of yourself and talk to you soon.